

MEDICINE AND SOCIETY

From Particularities to Context: Refining Our Thinking on Illness Narratives

Annie Le, MPH, Kara Miller, MA, and Juliet McMullin, PhD

Abstract

This paper examines how illness narratives are used in medical education and their implications for clinicians' thinking and care of patients. Ideally, collecting and reading illness narratives can enhance clinicians' sensitivity and contextual thinking. And yet these narratives have become part of institutionalizing cultural competency requirements in ways that tend to favor standardization. Stereotyping and reductionistic thinking can result from these pedagogic approaches and obscure structural inequities. We end by asking how we might best teach and read illness narratives to fulfill the ethical obligations of listening and asking more informative clinical interview questions that can better meet the needs of patients and the community.

Introduction

Illness narratives are a genre wherein an illness and its effect on the patient's life are told as an autobiographical or biographical account. As Kleinman [1] and Frank [2] have argued, illness narratives are forms of meaning making. They provide insight into how patients and clinicians understand the why and how of illness causation and treatment, including how illness processes are linked to the broader social and structural contexts of patients, their communities, and their clinicians. As a form of meaning making, illness narratives can be created in a clinical encounter, wherein physicians and patients co-construct a therapeutic agenda [1, 3, 4] that weaves together what the patient and the clinician know about the illness and its context.

The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures [5] is an example of an illness narrative that illuminates cultural, economic, and ethical meanings in a patient's illness. *The Spirit* describes the beliefs and practices of the Lee family, Hmong immigrants living in Central California, and those of the health care and social service workers, who were, from their experience and cultural positions, attempting to provide excellent care for Lia, the young daughter who has epilepsy. The story gives us profound insight into how, despite a medical team's best efforts, inadequate care can arise from miscommunication, failure among clinicians to reflect on their own cultural and economic positions, rigid institutional policies and procedures, and systemic inequities.

In the 20 years since the publication of *The Spirit*, conversations about the role of illness narratives in medical training have abounded. In this article, we examine the use of illness narratives in cultural competency training and their implications for clinicians' thinking and care of patients. We argue that an approach to teaching narrative that tends toward standardization and reductionism may impede students' understanding of how to authentically engage with patients' stories and the structural inequities described in illness narratives. We end by asking how we might best teach and read illness narratives with a view to asking clinical interview questions that are more informative and better meet the needs of patient-centered and community-engaged care.

Teaching Cultural Competency with Illness Narratives in Medical Training

Illness narratives such as *The Spirit* have become tools to demonstrate that medical students have acquired cultural competency [6], which is required by the Accreditation Council for Graduate Medical Education (ACGME) [7, 8]. At the heart of using illness narratives and teaching cultural competency is a desire to ensure excellent care for all patients—recognizing that patients face differential experiences and barriers to care—and to contribute to reducing health disparities related to race and ethnicity [9]. Nevertheless, given the demand on medical education to accommodate and standardize new scientific knowledge [10], individual and structural contexts of narratives can be reduced to lists of cultural attributes. Here, we show that the problem that *The Spirit* and similar illness narratives pose for medical training resides not in the narrative itself but rather in how such books are taught and interpreted [11, 12].

The theory and practice of cultural competency have been critiqued for the potential pitfalls of stereotyping and simplifying the meaning of culture and who “has” culture [13]. Similarly, DasGupta notes that a hallmark of cultural competency is a reliance on “lists” of fixed cultural characteristics [14]. Scholars in both the discipline of anthropology, whose ethnographies may be used to create such lists, and medicine, whose practice depends on sensibly and sensitively understanding a patient's narrative [15], argue that when reading illness narratives such as *The Spirit* we must do so as agile and complex thinkers who can move beyond lists [13, 15]. When reading illness narratives, teachers and students should attend to not only the cultural context but also the social and [structural contexts](#) that make complicated treatments nearly impossible for under-resourced patients to follow.

For the Lee family, “failures to comply” with the treatment regimen led to Lia being moved to foster care for several months. Lia Lee's physicians were regularly changing her medications, trying to find the right anticonvulsant for the progression of the seizures. This constant fine-tuning, however, never included a conversation about how Lia's parents understood the reason for the changes or their ability to repeatedly access different medications. Importantly, the physicians also did not take into account the

parents' knowledge of how each medication was affecting Lia. Rather than reading this moment of "noncompliance" as the failure of treatment comprehension by an immigrant family, the moment should be read with attention to economics, access, and the clinician's ability to listen with care [16].

To achieve this type of reading, teachers and students not only must focus on data points about their patient's culture or illness but also must critically reflect on their own assumptions and grapple with both structural conditions that produce inequitable access to resources and structural interventions that do not meet the needs of the patient [13, 14]. Engaging in [critical reflection](#) can lead clinicians to ask questions of their patients, clarifying and attending to the combined individual and contextual factors that might affect patients' health, such as how patients understand their medication and its effects, being unhoused, having multiple jobs to make ends meet, or living in neighborhoods that are subjected to greater amounts of pollution or violence [14, 17, 18]. These questions can provide an opening for creating an illness narrative with the patient and his or her family about a treatment plan that more appropriately meets the patient's health care needs.

When analyzed critically and holistically, illness narratives provide insight into the context of patients' lives, create and sustain empathy, and spark critical reflection on implicit biases and structural inequities. Teaching illness narratives to best effect involves expanding beyond the framework of cultural competency. An authentic engagement with the narrative can yield lessons for clinicians to engage with their health care team and with their patients and to provide care that broadens the scope of considered contexts. In this way, the scope of interventions with which clinicians can engage are similarly broadened.

Particularities, Peculiarities, and Pedagogy: Where It Goes Wrong

Given the potential for illness narratives to bring attention to the nuances of social and structural context, how is it that the cultural competency lens seems to limit readers to *particularities* about their patients? In medical and anthropology courses, discussions about narrative and culture can revolve around cultural *particularities* as *peculiarities*. One such particularity is food. In *The Spirit*, Hmong foods are recurring motifs. The supposed peculiarity of their foods is mentioned by doctors who care for Lia's mother in the hospital after she gives birth to Lia. In anthropology classes using *The Spirit* taught by one of us (KM), students frequently focus their discussions on the descriptions of foods and other alluring or unfamiliar practices of the Lee family. Although food is indeed meaningful, the microscopic focus on this aspect of a patient's context alone can be problematic if it leads to exoticizing, pigeonholing, or simply distracting from care.

Similarly, a course guide familiar to one of us (AL) that introduces students to the topic of cultural competency opens by stating that our diverse society "offers us the chance to

enjoy many of the world's cuisines. It also means that we get to experience many of the world's languages." At best, this perspective only goes as far as recognizing that clinicians may encounter patients who have different backgrounds and life experiences than themselves. At worst, it may position the clinician as a mere recipient of information about his or her patients, rather than as an active participant in developing the patient-clinician dynamic. Medical students are accustomed to receiving a straightforward rubric for didactic science competencies, and this expectation of standardization may be inadvertently transferred to the expectations of their approach to clinical encounters with the result that cultural particularities may be gathered as data points, consistent with the clinical manner of collecting data points about a presenting illness. This scientific way of knowing is in direct contrast with understanding the meaning of the narrative [19] and the context in which that narrative occurs [1, 4, 13].

In this reductive framing of culture, cultural competency can slide into stereotyping and ultimately inadequate care. For example, the cursory reading and teaching of narratives regarding foods associated with different cultures, paired with the reductionist thinking that certain foods are always consumed by specific cultures, can lead to overly simplified questions in the clinic. One of the authors (AL) reports that, having taken several classes and workshops about cultural competency, a common refrain is that the patient must be questioned about assumed cultural food practices. Given the exact same example several times by instructors, she (AL) found herself asking a Latina patient with diabetes, "How many tortillas do you eat?" prior to asking broader questions about diet. The clinician missed the opportunity to open the conversation to nutrition in general, food access, and exposure to obesogenic environments. Importantly, this patient did not even like tortillas.

Indeed, the pedagogical framework within which illness narratives are taught has consequences for clinical practice. When illness narratives and cultural competencies are reduced to stereotypes, the constellation of forces that affect health outcomes beyond the individual level of behavior, beliefs, and attitudes are obscured, and the bounds within which the clinician is capable of addressing patient needs is constrained. More helpful for lifelong learners than a rubric of cultural competencies is initiating the exploration of broader contexts of care that foster partnerships with others, knowing oneself in a reflexive manner, and co-constructing illness narratives and therapeutic agendas.

Thinking about Care and Context

To hear and listen to someone's story creates an [ethical obligation](#) [20]. This ethical obligation requires something of the listener in general and, in this context, of the physician in particular: a diagnosis, a referral, a space for expressing and bearing witness to suffering and social inequity. All of these actions require care—not just care in its commonly used sense of providing health care—but care as something considered by an

active, agile, and complex thinker [15]. To use illness narratives to achieve this kind of care and thinking requires instructors to carefully attend not simply to the descriptions of cultural attributes but to the contexts in which the medical encounters occur [1, 11, 12].

One of the roles of clinicians is to act as gatekeepers, as they command knowledge of and access to medical and social services resources. Consequently, clinicians' interpretations of and interactions with patients' narratives can amount to provision or denial of resources. When illness narratives are not co-constructed by clinician and patient, inappropriate or inadequate treatment can follow, as we see in *The Spirit*. An understanding of how one cares within broader contextual, structural perspectives would make material resources and power dynamics more explicit and ideally compel one to assume a role as advocate for one's patients, affirming their agency while providing access to available social service resources and advocating for access where it is limited.

Care and Context at the Core of Medical Practice

Given the complexity of the narrative in *The Spirit*, to reduce it to lists of cultural attributes is to not completely teach or read the narrative. This text and other illness narratives [21-23] provide ample detail to examine the cultural context as well as the institutional, economic, and political structures that influence health care and health-related inequities. Expanding beyond the hyperfocus on cultural particularities to achieve a structural outlook could assist clinicians in becoming comfortable with the discomfort of not knowing and categorizing their patients offhand, committing to developing relationships through open-ended questions and listening, and seeking to co-create therapeutic agendas that better account for context [1, 3, 4, 20].

Teaching with illness narratives in medical education could be improved by explicit training in how to decipher and analyze cultural and structural contexts [24]. Several pedagogical approaches have been described that avoid the pitfalls of cultural reductionism. Kleinman and Benson [25] have proposed an ethnographic approach to considering culture beyond lists of particularities. DasGupta [14] provides a methodology for engaging students in open discussion of the cultural and structural contexts in illness narratives. Metzl and Hansen's [17] structural competency framework describes an approach to teaching about the structural conditions that shape the patient's world. Metzl and Hansen argue that this approach can improve the quality and comprehensiveness of clinicians' questions about patients' life circumstances and provide them with tools to make a difference in their patients' lives by preparing them to serve as advocates for social services and structural change. Integrating these approaches can provide a more comprehensive foundation within which illness narratives can be taught to their fullest potential, solidifying our obligation to engage with patients and their complex narratives [20], which hold potential for providing meaningful and excellent medical care.

References

1. Kleinman A. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York, NY: Basic Books; 1988.
2. Frank AW. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago, IL: University of Chicago Press; 1995.
3. Charon R. *Narrative Medicine: Honoring the Stories of Illness*. New York, NY: Oxford University Press; 2008.
4. Launer JMN. *Narrative-Based Primary Care: A Practical Guide*. Abingdon, UK: Radcliffe Medical Press; 2002.
5. Fadiman A. *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*. New York, NY: Farrar, Straus, and Giroux; 1997.
6. DasGupta S, Meyer D, Calero-Breckheimer A, Costley AW, Guillen S. Teaching cultural competency through narrative medicine: intersections of classroom and community. *Teach Learn Med*. 2006;18(1):14-17.
7. Accreditation Council for Graduate Medical Education. ACGME common program requirements. https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/CPRs_07012016.pdf. Effective July 1, 2016. Accessed January 27, 2017.
8. Ambrose AJH, Lin SY, Chun MJB. Cultural competency training requirements in graduate medical education. *J Grad Med Educ*. 2013;5(2):227-231.
9. Brach C, Frasserirector I. Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Med Care Res Rev*. 2000;57(suppl 1):181-217.
10. Lambert DR, Lurie SJ, Lyness JM, Ward DS. Standardizing and personalizing science in medical education. *Acad Med*. 2010;85(2):356-362.
11. Taylor JS. The story catches you and you fall down: tragedy, ethnography, and "cultural competence." *Med Anthropol Q*. 2003;17(2):159-181.
12. Jurecic A. *Illness as Narrative*. Pittsburgh, PA: University of Pittsburgh Press; 2012.
13. Kagawa Singer M, Dressler W, George S; NIH Expert Panel. Culture: the missing link in health research [published online ahead of print July 18, 2016]. *Soc Sci Med*. doi:10.1016/j.socscimed.2016.07.015.
14. DasGupta S. How to catch the story but not fall down: reading our way to more culturally appropriate care. *Virtual Mentor*. 2006;8(5):315-318.
15. Bleakley A. *Medical Humanities and Medical Education: How the Medical Humanities Can Shape Better Doctors*. Abingdon, UK: Routledge; 2015.
16. SmithBattle L, Lorenz R, Leander S. Listening with care: using narrative methods to cultivate nurses' responsive relationships in a home visiting intervention with teen mothers. *Nurs Inq*. 2013;20(3):188-198.
17. Metzl JM, Hansen H. Structural competency: theorizing a new medical engagement with stigma and inequality. *Soc Sci Med*. 2014;103:126-133.

18. Kumagai AK, Lypson ML. Beyond cultural competence: critical consciousness, social justice, and multicultural education. *Acad Med*. 2009;84(6):782-787.
19. Bruner JS. *Actual Minds, Possible Worlds*. Cambridge, MA: Harvard University Press; 1986.
20. Charon R, Montello M. *Stories Matter: The Role of Narrative in Medical Ethics*. New York, NY: Routledge; 2002.
21. Livingston J. *Improvising Medicine: An African Oncology Ward in an Emerging Cancer Epidemic*. Durham, NC: Duke University Press; 2012.
22. Briggs CL, Mantini-Briggs C. *Stories in the Time of Cholera: Racial Profiling during a Medical Nightmare*. Berkeley, CA: University of California Press; 2004.
23. Holmes S. *Fresh Fruit, Broken Bodies: Migrant Farmworkers in the United States*. Berkeley, CA: University of California Press; 2013.
24. DasGupta S. Narrative humility. *Lancet*. 2008;371(9617):980-981.
25. Kleinman A, Benson P. Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS Med*. 2006;3(10):e294.
<http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.0030294>. Accessed January 27, 2017.

Annie Le, MPH, is a second-year medical student at the University of California, Riverside School of Medicine. She earned her MPH in community health sciences at the University of California, Los Angeles. She is passionate about participating in patient and community empowerment and building cross-disciplinary and community-engaged approaches to confront health inequity and structures of oppression.

Kara Miller, MA, is a PhD candidate in the Department of Anthropology at the University of California, Riverside. She is interested in care as a conceptual practice, as a moral compulsion, and as a form of relationality. Her research in southern Uganda and the United States examines bodily vulnerability and formative social entanglements of care.

Juliet McMullin, PhD, is an associate professor at the University of California, Riverside, where she is also the associate director of the Center for Healthy Communities. She is a cultural and medical anthropologist with research interests in the political economy of health and the role of narrative in medical encounters. To examine these larger questions she has focused specifically on topics related to medical knowledge and inequalities in cancer, cultural meanings of health, and pediatric injury. Her research practices emphasize community-based participatory research and the inclusion of students in projects.

Related in the *AMA Journal of Ethics*

[The Ethical Force of Stories: Narrative Ethics and Beyond](#), August 2014

[From *Doctors' Stories* to *Doctors' Stories*, and Back Again](#), March 2017

["Sickness Is a Place": The Foreign Culture of Illness](#), April 2012

[Structural Competency Meets Structural Racism: Race, Politics, and the Structure of Medical Knowledge](#), September 2014

[Tangles: An Illness Narrative in Graphic Form](#), August 2014

[Teaching Cultural Sensitivity through Literature and Reflective Writing](#), August 2007

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.
ISSN 2376-6980**